



Idaho Parents Unlimited, Inc. The Consortium of Idahoans with Disabilities

Children's Benefit Redesign – Parent Feedback Survey Report

January 12, 2011

This report was created in response to a large number of calls to our agencies regarding the changes being made to Medicaid services for children with disabilities in Idaho.

The survey was created using Survey Monkey and was distributed via electronic email listservs and social networking sites, statewide. We will continue to collect responses, however, in an effort to provide quick feedback to both the Idaho Department of Health and Welfare – Family and Community Services as well as parents of children with disabilities, we have generated this report. Results are based on 195 respondents from December 20, 2011 thru January 12, 2012.

No comments made by respondents have been altered in any way. They have been entered exactly as they were in the original survey.

All survey responses are anonymous with the exception of those who agreed to share their contact information with the Department. To protect the privacy of those who did choose to share their information, a separate list will be given directly to the Department as the respondents did not agree to share their information with other organizations or individuals.

Due to the large amount of responses collected in such a short amount of time and the consistency in overall responses, we believe there is a need for more clarity and information to parents, as well as further training for regional staff.

On behalf of the Consortium of Idahoans with Disabilities and Idaho Parents Unlimited, we welcome any questions or comments.

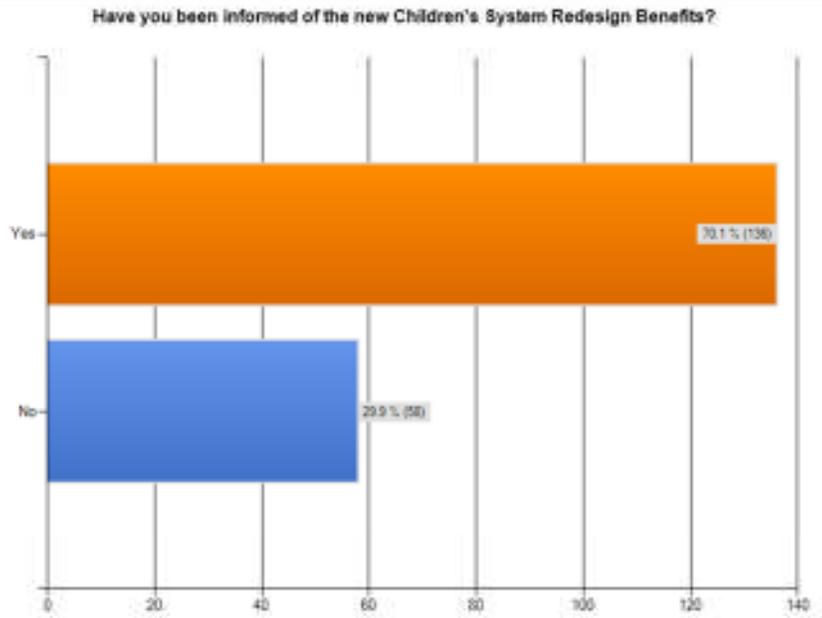
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Children's Benefit Redesign Survey – January 2012

1. Have you been informed of the new Children's System Redesign Benefits?

Answered Question 194
Skipped Question 1

Yes 70.1% 136
No 29.9% 58



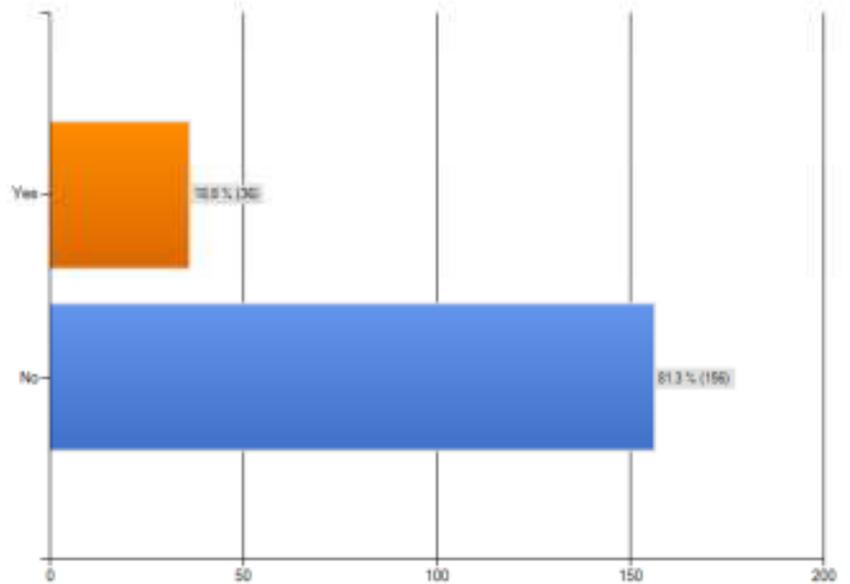
2. Are you currently participating in the new Children's System Redesign?

Answered Question: 192

Skipped Question: 3

Yes	36	18.8%
No	156	81.3%

Are you currently participating in the new Children's System Redesign?



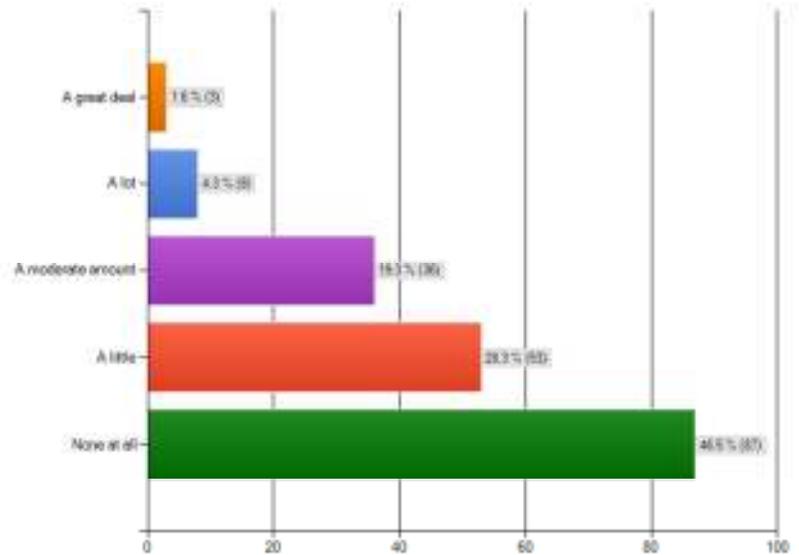
3. Do you feel the information you have received has been clear and helpful?

Answered Question: 187

Skipped Question: 8

A Great Deal	3	1.6%
A Lot:	8	4.3%
A Moderate Amount	36	19.3%
A Little	53	28.3%
None at All	87	46.5%

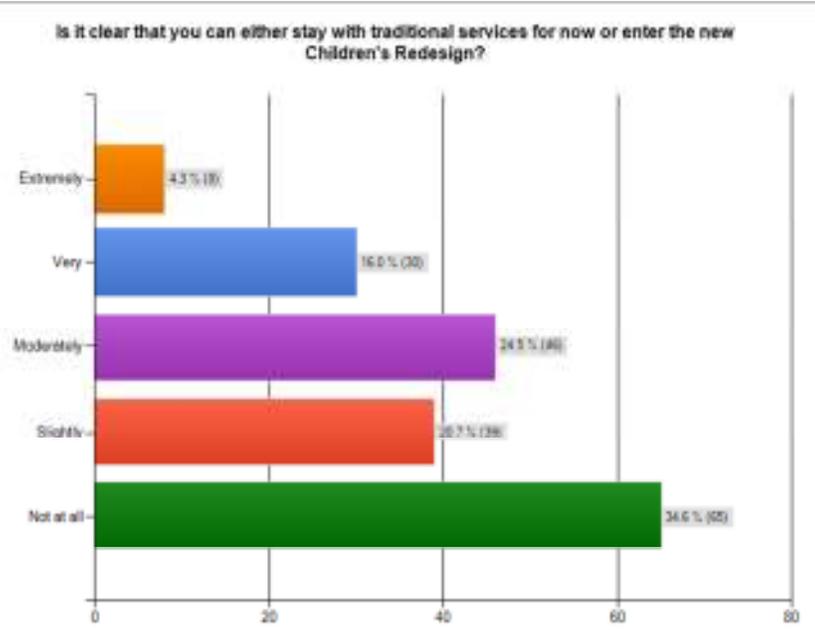
Do you feel that the information you have received has been clear and helpful?



4. Is it clear that you can either stay with traditional services for now or enter the new Children's Redesign?

Answered Question: 188
 Skipped Question: 7

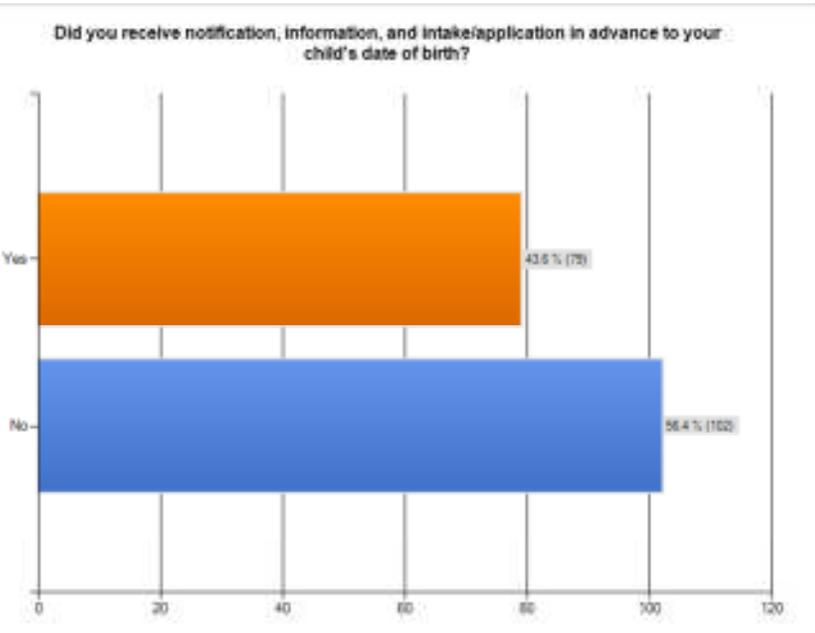
Extremely	8	4.3%
Very	30	16.0%
Moderately	46	24.5%
Slightly	39	20.7%
Not at all	65	34.6%



5. Did you receive notification, information, and intake/application in advance of your child's date of birth?

Answered Question: 181
 Skipped Question: 14

Yes:	79	43.6%
No:	102	56.4%



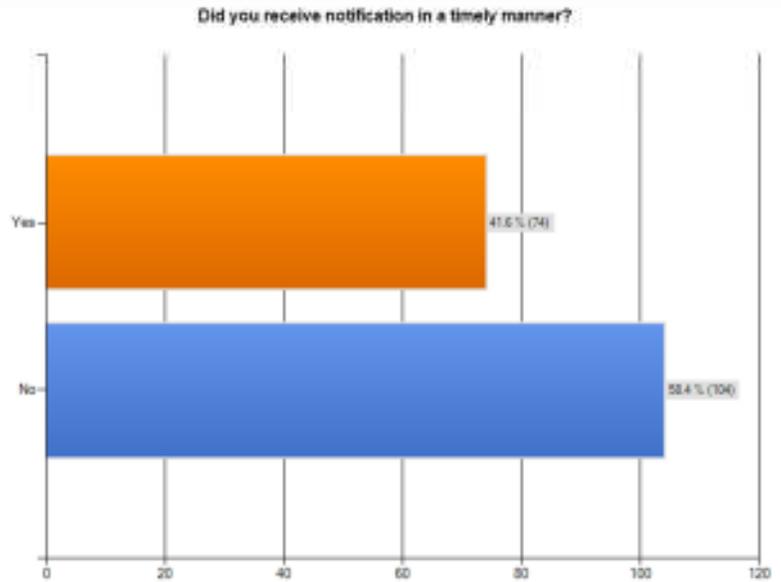
6. Did you receive notification in a timely manner?

Answered Question: 178

Skipped Question: 17

Yes: 74 41.6%

No: 104 58.4%



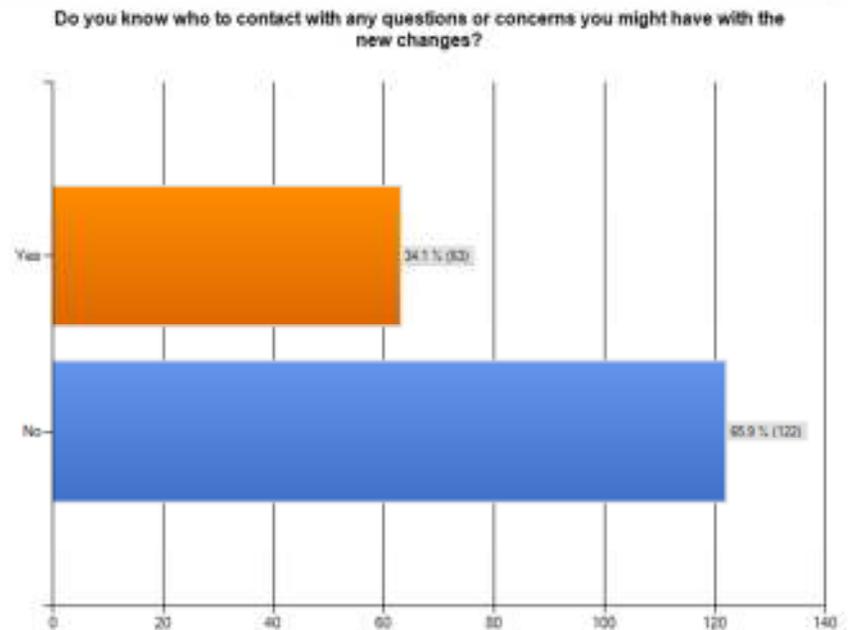
7. Do you know who to contact with any questions or concerns you might have with the new changes?

Answered Question: 185

Skipped Question: 10

Yes: 63 34.1%

No: 122 65.9%

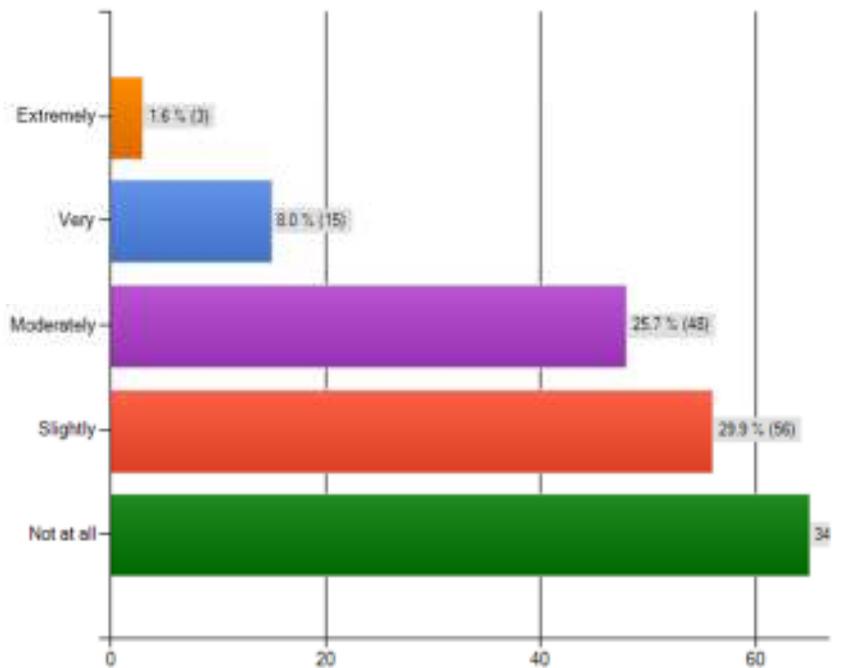


8. Do you understand the different types of services available through the Children's System Redesign?

Answered Question: 187
 Skipped Question: 8

Extremely	3	2.4%
Very	10	8.1%
Moderately	23	18.5%
Slightly	39	31.5%
Not at All	49	39.5%

Do you understand the different types of services available through the Chi System Redesign?

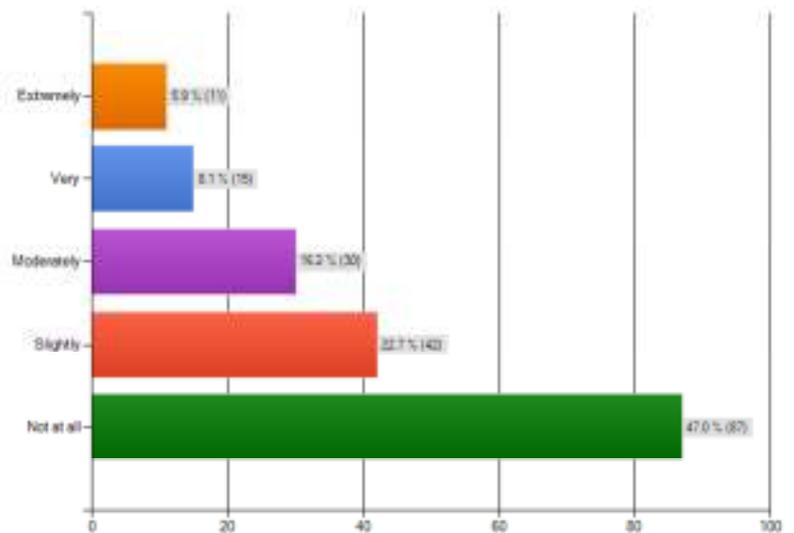


9. Do you feel confident in making the proper decisions and choosing the right services available?

Answered Question: 185
 Skipped Question: 10

Extremely	11	5.9%
Very	15	8.1%
Moderately	30	16.2%
Slightly	42	22.7%
Not at All	87	47.0%

Do you feel confident in making the proper decisions and choosing the right services available?

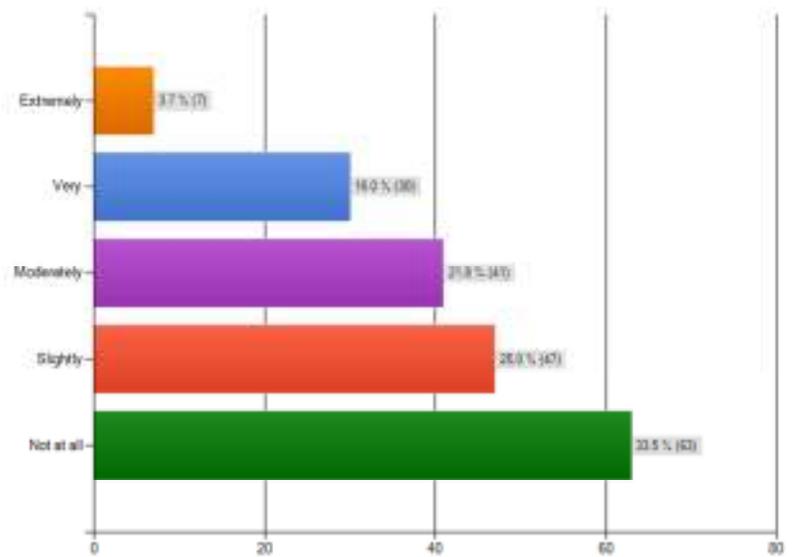


10. Have you been informed about the option of family directed services for your child?

Answered Question: 188
 Skipped Question: 7

Extremely	7	3.7%
Very	30	16.0%
Moderately	41	21.8%
Slightly	47	25.0%
Not at All	63	33.5%

Have you been informed about the option of family directed services for your child?

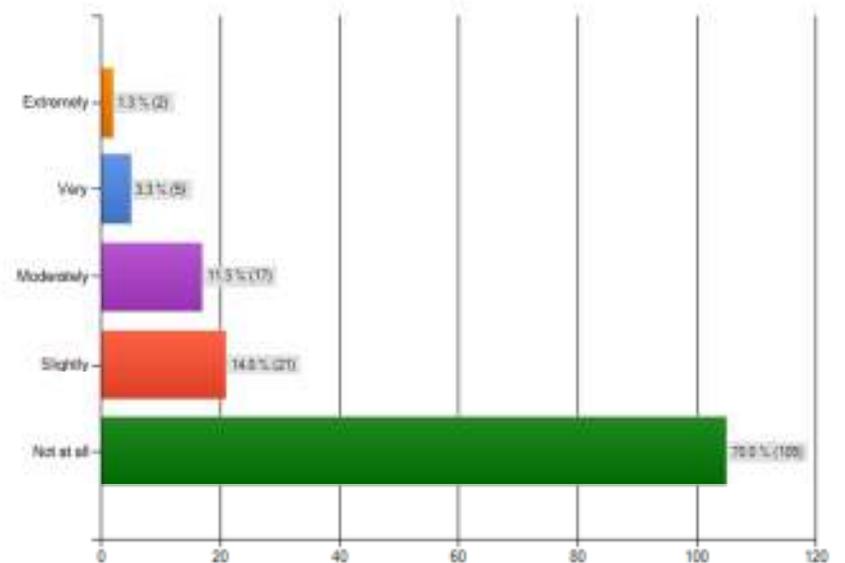


11. If you chose the family direction, did you receive adequate training to allow you to implement this option?

Answered Question: 150
 Skipped Question: 45

Extremely	2	1.3%
Very	5	3.3%
Moderately	17	11.3%
Slightly	21	14.0%
Not at All	105	70.0%

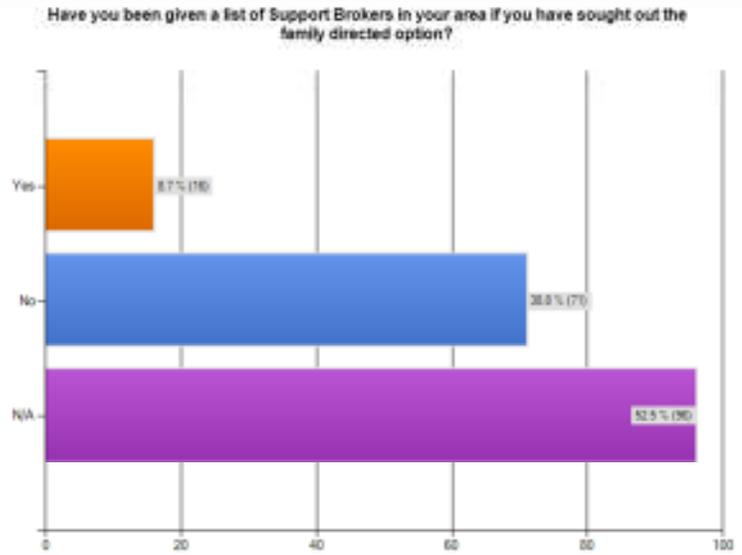
If you chose the family direction, did you receive adequate training to allow you to implement this option?



12. Have you been given a list of Support Brokers in your area if you have sought out the family directed option?

Answered Question: 183
 Skipped Question 12

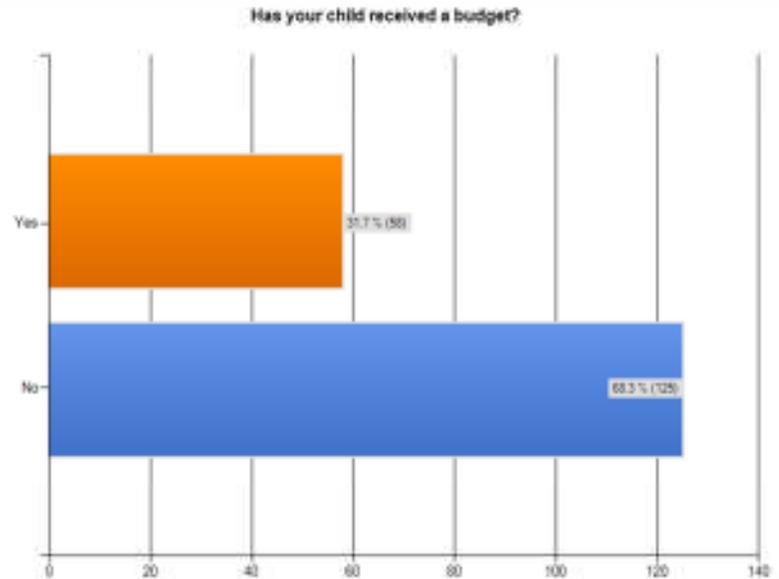
Yes: 16 8.7%
 No 71 38.8%
 N/A 96 52.2%



13. Has your child received a budget?

Answered Question 183
 Skipped Question 12

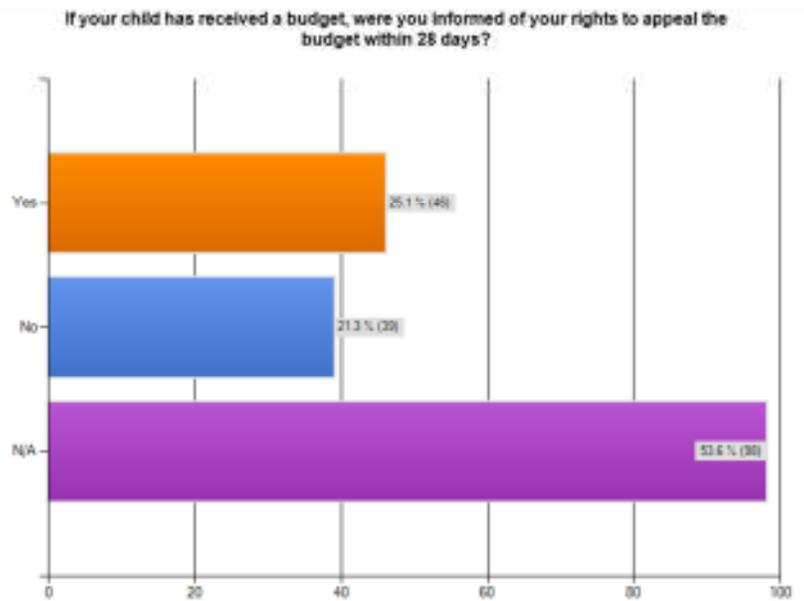
Yes 58 31.7%
 No 125 68.3%



14. If your child has received a budget, were you informed of your rights to appeal the budget within 28 days?

Answered Question: 181
 Skipped Question: 14

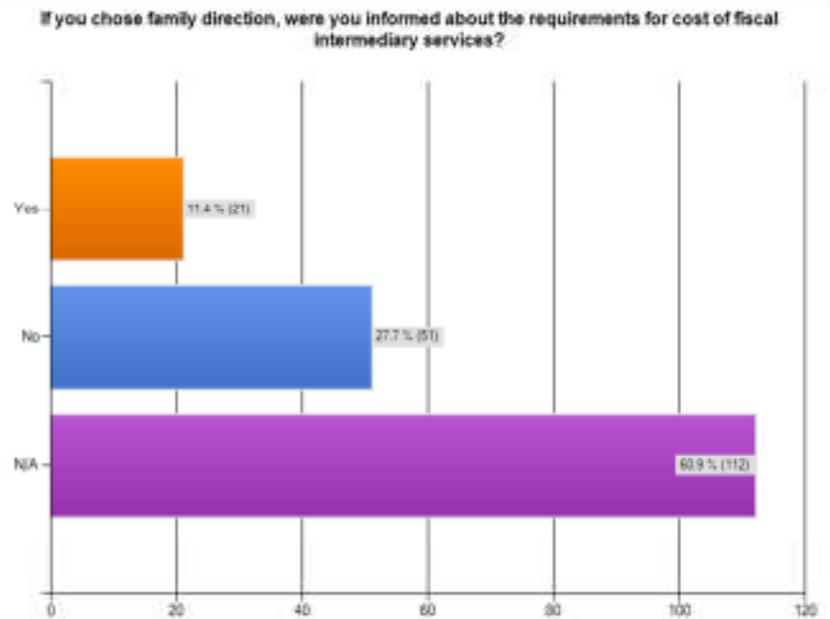
Yes: 46 25.1%
 No: 39 21.3%
 N/A: 98 53.6%



15. If you chose family direction, were you informed about the requirements for cost of fiscal intermediary services?

Answered Question: 184
 Skipped Question: 11

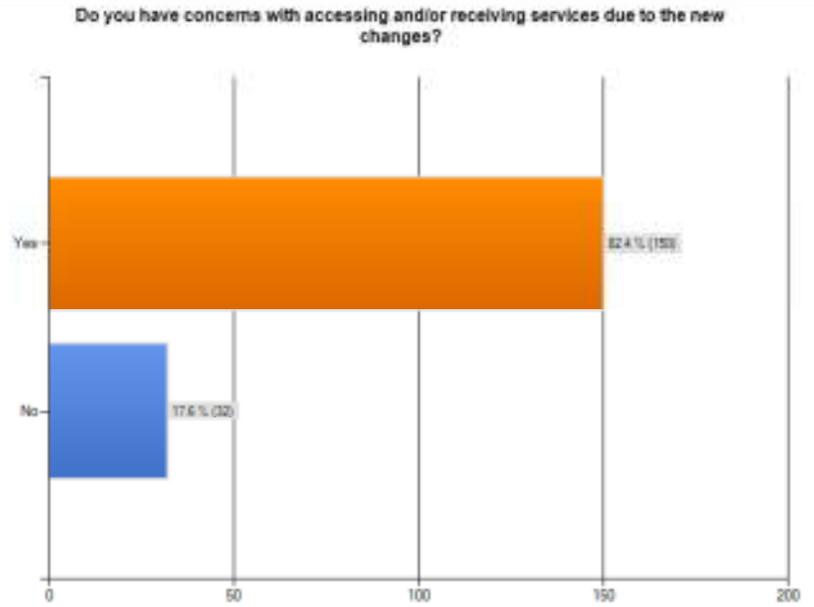
Yes: 21 11.4%
 No: 51 27.7%
 N/A: 112 60.9%



16. Do you have concerns with accessing and/or receiving services due to the new changes?

Answered Question: 182
Skipped Question: 13

Yes: 150 82.4%
No: 32 17.6%



16. B: What Services/What Concerns:

1. The menu of services looks great, at first glance. However, for children in rural locations that have not had access to IBI or other interventions and are over 7 yrs, they will see a drastic decrease in services. Medicaid's response to that is Self Direction, as a support broker for the adult, I have seen the issues with the SD model, and would not recommend it for children. Furthermore, in Rural locations SD will not replace much needed interventions.
2. We are still seeking out a good person to work with my daughter.
3. I am only again starting to get services back in place for my son as all were lost due to the judicial system and he has to start all over
4. IBI in school
5. Developmental Therapy. My concern is related to the budget and significantly limited hours that my child will be able to access therapy. Another major concern I have is regarding Service Coordination, this service in and of itself has been a huge help and I do not like the idea of it being taken from us. I am also concerned about the time it will take to manage my child's services through the family directed plan. I am a single parent and I work full time as it is, adding what seems like it would equate to another full time job to my plate is daunting.
6. I'm concerned my child won't receive the level of service they can currently receive
7. I am concerned that even with the maximum budget, my son will only be able to receive six hours of habilitative intervention instead of the 22 hours of IBI he currently receives and I am afraid he will regress.
8. Living in a rural area I am not sure at all what services will be available and have concern if there will be providers.
9. The budget is way less than Medicaid paid last year for my Childs dt
10. I have not received any information about anything in this survey until today....
11. The budget amounts are low making access to services limited.
12. school based, therapy, PSR , IEP focused services
13. Concerned that my child will lose current services.
14. Limited hours in the summer when there is no school available and many children with disabilities need additional support so their parents can work. Reimbursement rate for respite care is so low I don't know how anyone can offer that service.
15. I am concerned that my child will fall through the cracks and not have eligibility for the services he needs to keep him in the home environment
16. Staying with traditional services
17. any, it is all confusing
18. I am a supplier and am not aware of this program or if it affects Medical equipment
19. All, especially IBI
20. I am still uncertain as to how the changes will effect my three special needs children that we adopted from foster care?
21. I have not been told anything nor received anything other than this. I do not even know if my daughter qualifies.
22. All of it I am very skeptical of this and do not agree with it!
23. ALL !!!
24. Have no info about anything
25. One
26. my child receives an extension of hours with his new budget he is being cut almost 70% of IBI services he was previously receiving!!!! from 30 hrs to about 6-8!!!!!!!
27. I am worried that my child will loss occupational therapy.
28. will he be cut off seeing his cousilor? Will he not get surgeries he may need?
29. The budgets I have seen are less than 1/3 of the services which my child has now and I am afraid I will not be able to get the needed services to teach my child to live independently as an adult.
30. My child is an adult, but I had no information about the Program you discribe. Is he impacted as an adult in cfh care?
31. I am frustrated that we have to choose between developmental and psr when we can clearly see the differences in the services. I am frustrated that we cannot have both. 2 of our children need both.
32. I'm afraid with the new system I will have to choose therapies and be without necessary services.

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33. I do have alot of questions but I am scheduled to take a class in January to help with the self directed process.
34. Service coordination and budget restrictions.
35. The Self Direct program would allow us more flexibility with services for our daughter but as paid care givers in that program, our income would be taxed and change our income tax requirements. Now, with a CFH, that income is tax exempt. Therefore, we chose not go go with Self Direct.
36. all
37. Children won't get enough services under redesign.
38. The budgets are inadequate. Do not understand what the new
39. I have not recieved any info at all with the changes being made for my disabled son on medicaid. I could not answer about the money because I have no clue as to what is happening. It bothers me quite a bit after seeing that my kid will get an amount and have a broker??? I have not recieved anything at all with what benefits he will be able to have and not have. that some things he seriously needs could get cut. what is family direction?
40. PT/OT/Speech, I've been told they are cutting back the number of visits you will be allowed per year.
41. I have been with Innovative for years and i if possible would like to stay with them. They know what is going on and i don't feel like starting over.
42. I need complete information regarding all the new changes. I have not received any information regarding the changes.
43. IBI therapies
44. Just have no idea how it works and when we were supposed to start.
45. I want to know what the new budgets will be for my children but I was told that if I ask the department to figure it out for me then I am obligated to go to the new system. Nobody seems to know anything about family directed. I can not find much information online. Service coordinators and DDA's do not know much.
46. In the Redesign program a child with autism is not given enough money for sufficient IBI hours. This will be a huge financial strain on our family. It has been proven that with 25-30 hours of IBI a week that children with autism can progress enough that they no longer need services. (the new program will only cover the cost of 10 hours a week) These services are most beneficial with younger Children. We have also struggled with being able to get intensive services before age 3. The infant toddler program did not provide enough for our son's needs.
47. If IBI over HI is selected & there are no way for IBI therapists to be trained who will provide the services our child needs?
48. Services are extremely limited! We are facing institutionalization due to a lack of IBI and other services under the redesign!!!
49. Knowing if the person has the right amount of training
50. I don't understand.
51. IBI services at an effective level of time.
52. Accessing EPSDT for medically necessary therapy.
53. Would like have a written handbook with all options and information for things such as if I change my mind when and if I can change. Also lists of contacts. I do not like the idea of loosing a coordinator. My have been very helpful navigating everyday issues as they arise. So far I have attended meetings and the info from my coordinator have been the easiest to understand.
54. This will limit the amount of services my child can receive and we will not have the same kind of support from providers in the area.
55. I was not aware that there were different Medicaid levels that affected the choices available for my child. Because my child is on low income Medicaid I do not have a choice and I only have the traditional services available for my child.
56. How do I get help going through this process? When will my service coordinator be taken away? Is she getting paid to help me? Who is responsible for helping me go through the ICDE process?
57. The Redesign does not meet my child or my families needs at all. They said it was cost neutral..... it is not. It has cut services and programs that my child needs.
58. Speech, OT, PT, Counseling, IBI, DT...Everything
59. budget inadequate to meet my childs needs as determ ined.
60. I don't know what my child's budget is going to look like and I don't know what my child will qualify for once we receive the budget.

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61. I am still unsure about what will be allowed under Family Directed Services but I have confidence the Dept will help me through the process.
62. Continued access to epsdt? No one knows the answer. Provider training not accessible. Serious staff shortage to implement ibi. Of course families are losing their service coordinators during the time they need them most. Concerns about skills of our state employees- especially at the central office. They need to remember they are PUBLIC officials. Children with DD being denied access to CMH services simply because they have a developmental disability. Fair hearings process not fair. understanding of the differences between current services and the new list of services. means ect.
63. I am very concerned about receiving adequate services for my son and have yet to have any clear Habilitative services are very unclear to me. I cannot find any clear definition of what Habilitative supports
64. What services
65. Who will attend IEP meetings with family?
66. Some department employees do not give parents the option of keeping traditional services and seem to force the re-design onto people that do not have a strong voice. Plans that have been coming back are poorly written and are hard to follow for parents and providers. Although the system itself may become sound it is not properly funded and many children will fail under the new system. The budgets are inadequate for children older than 5.
67. I would like to know what is happening with this. I have not received any information.
68. everyone is receiving conflicting information...don't know who to believe
69. misleading communication--budget assigned is not individual to meet needs of child, so severe children will be receiving a 75% cut in services due to the generic budget assigned.
70. Supply in areas is a HUGE concern. People are not trained nor is there training available. Also, the budget is inadequate an inappropriate since everyone is simply placed into tiers. How is that individualized?
71. I think it seems like it will take a lot of time to administrate and I am worried that the budget will not be enough
72. Will TriCare pay for the things that Medicaid wont on the redesign. What affect does the system have on Katey Beckett?
73. I am concerned that I will not continue to receive the services I am receiving now and the time my child will have to develop to their full potential.
74. respite care for our child
75. I feel completely in the dark. Don't understand this new system, and don't have information. This survey has been my first information about it.
76. yes. I am just worried that my child won't get the same quality. I love how the program is now and I value the help of the center we go through. Our service coordinator is fabulous. I am very nervous about the changes. We have opted not to change yet.
77. Budgets only allow a fraction of previous services
78. Don't know, I will have to find out what this is all about.
79. I am hoping that emergent developmental therapies would be an option as part of the re-design. Specifically the Relationship Development Intervention program.
80. no information has been offered
81. It is too confusing.
82. IBI as it is so expensive and we would qualify for the max amount of hours
83. My children have been put on "hold" and left without services because the "change" is coming. No one knows exactly what to do. Seems they are all waiting.
84. Service coordination
85. The budget for my child is woefully insufficient to meet even a tenth the level of services she currently needs which are already insufficient to meet her needs. Continued intervention is absolutely necessary to help my child learn the skills necessary to keep her out of institutionalized care as an adult. A service that will cost hundreds of thousands more over the sixty to eighty years of her adult life.
86. Yes, I am afraid that we won't have enough money to cover all the services we are requesting. Right now son only qualifies for 6 hours of IBI services a week.
87. The whole design is just plain confusing, and then to take away our service coordinators, the one who helps us

through all this--just makes it worse.

88. Parents have not been trained on how to use the consumer direct side of the program.

89. I need someone to help with my child's skills that is sufficient in quantity and quality. Uncertain if the new services will take care of my child's needs

90. Seriously, the red-tape involved with accessing medicaid is absolutely insane. It shouldn't be so hard to access services when a child is severely disabled. Calling to get information or get answers to questions involves HOURS on the phone with DHW. Parents with children who have disabilities DO NOT HAVE TIME to get through the hoops and red-tape. We are busy managing seizures, major health needs, or other parent related duties. I guess the best way for the state to save \$ is to make services harder to access, so parents give up. Great work DHW.

91. Even though many have been given a "choice" to stay with traditional services for the time being, there is currently a shortage of therapists who are IBI certified, and it is my understanding that IBI certification training is no longer being offered. There are 9 months left before the "mandatory" transition date (at least the latest info that I have received). My children, and others, need access to services now. I was told by the IBI Coordinator at my sons' DDA that she has had people with Master's Degrees and related work experience who have come in to apply for jobs, but she can not hire them because they are not IBI certified. We need an IBI certification course to be offered as soon as possible!

92. The information was so schetchy at first. Then when more information was available it was more confusing, then the back stepping. The whole thing was just too confusing. My husband and I have a college education and are right on top of our little guys therapies and what we are supposed to be doing and it still was confusing for us.

93. My child's doctor has prescribed more behavior therapy then the budget amount allows for. The reduction is drastic...almost 75% once he goes into the redesign. He is currently getting it through EPSDT because his doctors have found it medically necessary but when the State takes off IBI off the State Plan this year Idaho Medicaid has not informed me how to apply for behavior therapy through EPSDT.

94. all

95. I am concerned about the new budget amount. I am not clear if that applies this year though I didn't opt into the Family Directed Services? What if the child has two parents that each want to control the services and budget? How will that work? What protections does the child have if the parent fails to keep up with the requirements of Family Directed Services?

96. Why can't you people just leave well enough a lone. When something works why break it? I am very happy with having my service cordinator that was of my choosing and not the states. I perfer to make my own choices not have someone else tell me this is what you get.

97. need clarified information

98. I honestly have no idea what this is about and it makes me extremely nervous - because Health and Welfare likes to surprise providers with a lot of changes that everybody was 'supposed' to be informed about! But they are so very sorry if someone doesn't the their 'memo'! This is very disturbing!!!

99. I'm extreamly concerned with the limited budgets that will allow for about 1/4 of the therapy a severely autistic 8-year-old child currently recieves. (22 hours per week now of IBI vrs. about 6 hours per week of Hibilitative Intervention year round with the allowed budget)

100. The redesign appears to be skirting or violating federal law. The role out has failed to adequately or timely informed us of our rights and true alternatives. We had to call in order to even receive the package that is required for receipient birthday. OOPS! I realize there is a financial crisis, yet that should absolutely not authorize deception, obfiscation or failure to adequ

101. PSR and PCI, if more of the hours are to be cut. What types of services are for my child are available. Will my child's medical needs be met.

102. Yes, I do not want to lose service cordination. I understand that my child may recieve less services. I want to be able to change my mind if one choice is not working for us.

103. my child will be 18 this year, how will all the changes affect her

104. I was not impressed with the way the information was given. There were several bits of information that I felt were important, left out of the training classes. The whole time I was in thee class the push was for self direction the only time any other option was mentioned was if a question was asked. Very frustrating!

105. As Medicaid has always been, there is no exhaustive list of services available. I just hope I think of or hear of all the appropriate options for my child.

106. It seems to me that with the changes, there is a big push for families to choose the family directed route. I loved having a targeted service coordinator. They knew the ins and outs and all the options available to our family. I do not have the time to chase down all the details of getting services via the family directed route. The changes created a whole new layer of bureaucracy, didn't save any money, while cutting services to those who need them the most. Our daughter is severely challenged and will never be able to make her own way in this world. She will always need extensive supports. The budget we received is completely inadequate. Our appeal was denied, even though it was WELL documented by our physician as to her NEEDS. Coordinating services without a targeted service coordinator has been time consuming and challenging. Our family is very disappointed with the whole package of changes. The children who need the most services will not get them, creating huge burdens on families and the community.

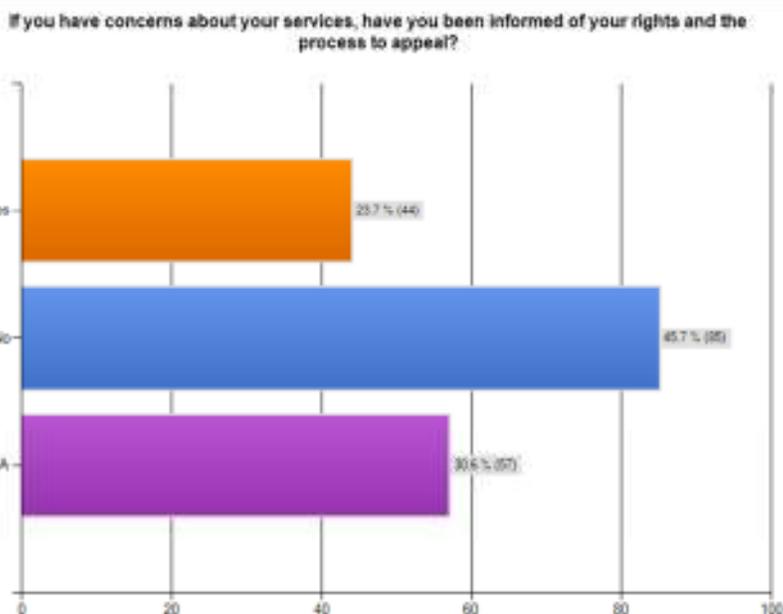
107. Any services that are similar to IBI or Developmental Therapy because from what I understand, those services are very expensive and the kids' budgets are very low.

108. I hope that my child can still receive developmental therapy along with counseling. I'm sick of the state thinking that PDD NOS is not a major concern.

17. If you have concerns about your services, have you been informed of your rights and the process to appeal?

Answered Question: 186
Skipped Question: 9

Yes	44	23.7%
No	85	45.7%
N/A	57	30.6%



Children's Benefit Redesign Survey – January 2012

18. Comments or Concerns:

1. Would be great to get some brokers closer to where we live.
2. See above. Also, as a person who works full time, I have a hard time seeing where I will have time to learn all that will be needed with this program. I have attended a class through Community Partnerships, but I am still somewhat confused. Especially if I choose the Family directed plan.
3. The process has been very confusing and a parent isn't sure where to go to find answers.
4. Having to do a 2nd test within 1 month of a Medicaid eligibility test was wasteful and pointless. The woman who did the zbar was young, inexperienced and was not prepared. She had not spoken with the person who had done the phone interview nor read the application they had requested I fill out and mail back. The office also insisted I bring my son to sit through the zbar.
5. I have not received any information about anything in this survey until today....
6. If my agency didn't give me information I wouldn't have figured out as much based on the training from the Department of Health and Welfare
7. I have no idea what you're talking about. My son has Medicaid. Is that what's changing?
8. I think the redesign is a positive change for Medicaid and will benefit my son. However, the process is overwhelming. There were too many "required meetings" that I felt were unnecessary. Our H&W contact has been extremely helpful, but is very hard to get in touch with. I don't think she has returned a phone call to me yet, I've always called again to reach her. A SIB-R was required, although 2 had been done in the 3 months prior to the redesign application. During that appt, my son was required to show up just to make sure he existed (these were the evaluators words). I'm hoping with time H&W can work out some of these issues. We felt that they were making the application process difficult in order to cause us enough frustration that we would give up. I've heard from other parents that did stop the process because there were just too many hoops to jump through.
9. This entire process is confusing and disruptive. We haven't used anything as a result and my child and our family have suffered. Even our service coordinator and staff have had problems getting answers. I requested a copy of our file, and received notices and emails, NO FILE 2 months later. Guess they sent it to someone else. 10. That was breaking HIPPA as well.
10. I don't understand why we are cutting benefits for the disabled and the elderly. As a culture, do we really want to create further dependency for these groups rather than more independence? Are these groups also entitled to a high quality of life which include independence? It's a sad commentary!
11. Children's benefit design is not ready for implementation, not well organized or informed.
12. My daughter's birthday is September so we have not yet received any information. I am concerned that we will not know enough to make an informed decision
13. What is this about? I want someone to call and tell me what is going on and if it pertains to my adult daughter.
14. The stopping of one on one DT does not work for my son and has set him back.
15. I am glad my daughter has a service coordinator to help be an advocate & adviser for us as a family and caregivers for our daughter. System seems very confusing
16. We were told extensions were only being granted to ICFMR/institutional level children!!!! Overall we are EXTREMELY dissatisfied with the redesign and as a parent who attended the local meetings we feel that we were GROSSLY MISINFORMED about the redesign and its advantages, reality is that services were cut and the process is more difficult so WHY the changes?????
17. I have no idea anything is changing
18. Our son is 34 years old. Please let me know if this survey applies to him.
19. The appeal process I have been part of is a no win for the person needing support. You can not win when the only criteria is that Health and Welfare did the assessment tool correctly when the tool itself denies needed funds.
20. I am frustrated that we aren't just given a packet with all of the information. I keep getting notices about meetings. I do not want to attend meetings. I do better with information I can read. I do not understand the whole process because the process is too complicated. I am just going with the parts I understand. My main concern was keeping our service coordinator and making sure all 4 of my children have psr & med management.
21. 2 of my children do need developmental services, but they need psr more right now. I am grateful for what we receive. I know the intervention they have received has been and continues to help them daily. Our goal is to help them become contributing members of society by the time they are adults. We would like them to not need Medicaid, we just don't know what the future holds. We are doing our best.
22. Every time I have questions no one has answers I have less than 60 days and one of my kiddos is supposed to

change to the redesign and I'm clueless as to what I'm supposed to do.

23. What exactly is the point? Those who have the power to do anything about it, aren't listening.

24. My daughter is an adult and receives DD waived services and my information may not apply to your survey. My answers are based on my experience with traditional Medicaid services and the Self Direct program.

25. service co. and client have received no information even though Birthdate was in Oct.

26. 1 hour a week is not enough services. There might as well be no services if DHW thinks such minimal hours are going to help these children.

27. We are currently in the process of applying. We have not yet received our budget (we assume it will be small as our son has an autism dx and is over age 6). We don't understand what the new services are, especially how habilitative supports compares to DT and IBI and we have major concerns about how well habilitative supports will be in helping our son progress compared to the progress we've seen with IBI. We are already certain we'll stay with the old system due to the budget issue. The new budgets are obviously inadequate for families that have no other resources to pay for therapies, etc. Have not been happy with the lack of information. Having new words for therapies without adequate descriptions seems to throw in a layer of misinformation and misunderstanding about the changes and the types of services that will be available. We feel like H&W is trying to obfuscate things in an attempt to keep clients mollified. Though obviously, if they had been forthright in the last legislative session that these changes would result in eliminating proven therapies and slashing budgets, they would have met with more resistance from the public.

Although there are FAQ's on H&W website, they did not answer all the questions that would logically occur to a parent or guardian to ask. We could not attend the parent meeting and it would have been helpful if H&W had provided the information covered on their website. The new services need much more in depth description so that we understand what we are choosing. Right now, Right now, the habilitative supports comes across sounding like babysitting and not like anything that would truly help a child with autism grow and progress. There appears to be no difference between habilitative supports and respite. From what little we have heard about the family directed option, we would never choose it as it sounds like it has the potential to waste the state's resources. Overall, we have not been satisfied with how H&W has handled the redesign. We do understand that the H&W budget is under a lot of pressure, but believe other things could have been done to investigate claims of waste, fraud and abuse. Reducing services to all clients was not a good way to save the state money. Also of concern is that there is that small age range of 3 to 6 for the Act Early Waiver. In many cases, the milder forms of autism such as Asperger's Syndrome and High Functioning Autism are not diagnosed until a child is older. Children could still be helped with IBI, etc. if they were diagnosed at age 7 or 8. Under the new system, the budget would be inadequate. We are not sure that the budgets for the Act Early Waiver are even adequate to meet the needs of a child with severe autism.

28. I don't know what services my son gets now under the redesign? I have not had anything mailed to me from H&W about the redesign and options or his rights or my son having a medicaid budget. after trying to answer this questionnaire and not knowing at all as a parent what is going on I am very very angry because I want to make sure my son is getting his needs met and at the same time wanting to make sure that I am choosing the best options available for him. Not having this info makes me worried because I want to make sure as his parent that I also am making the best choices because I love him and I want what is best for him.

29. I have decided to opt in early and just recently received the initial paperwork. I did not receive any updated information about the fiscal changes and right to appeal. I spoke to someone at H&W who told me about the changes to OT/PT & Speech, but she didn't have the full info to share so I'm still not sure how many visits will be allowed. Also the website it too cumbersome with where to go for info, updated info...I should be able to go to 1 spot and have all the info. Also still waiting for training info to be a broker & to attend the family directed training. No one seems to have that info.

30. I am not sure if i am already using the new redesign or not. This is all very confusing to me.

31. My two mental handicapped boys are 35 years old and only have the use of Adult Developmental Services.

32. No one... not even the department of Health and Welfare has productive answers.

33. Our family will be greatly impacted over the next 3 years depending on the amount of IBI services that we will need to private pay. We need to provide sufficient hours for our son while he is young.

34. I am a Casey Family Foster Home and a PCS home and I'm not sure how the redesign will effect the child in my home. I am also a CFH and the adult is on self direction which I asume is similar. I just wonder who will do all the work involved in seeting up the services. Setting up the Self Direction, was many hours of un paid work for me.

35. It seems that this system is so dysfunctional & confusing making families discouraged about seeking supports. This

- will only lead to more institutional placements which are more costly.
36. We are currently appealing our inadequate budget for the redesign.
37. Having a hard time getting all the paper work turned in
38. we had to opt in early so that my sons IBI services would not stop at a time when he is needing it the most he has gone from 22 hours to 6 hours a week.
39. Our appeal has been hindered by Health and Welfare not giving up information requested through the records request process. We feel our hearing is not fair at all.
40. Would like to see service coordination continue and a written handbook would be helpful with detailed information on each option how I can change or appeal. The pros and cons of each and contact information. The intake forms could be a little clearer on what documents are required and where we can obtain them.
41. I was not aware that I needed to have Social Security to make sure my child could have options in the new redesign plan. Because of M-CHIP Medicaid I don't choose anything but I didn't get to keep the developmental therapist that my child loved.
42. Even if I appeal..... and prevail.....DHW can overturn that decision. It is NOT a FAIR HEARING!
43. There are many pros and cons... This may work well for some families and not for others. A huge concern I have is the possibility of fraud that can take place with hiring friends/family to work with the client without any data being taken or goals implemented. Another concern I have is that the parents/providers are not being made aware to carry any form of insurance coverage for their employees. An employee injury, car accident, ect can cause a HUGE financial heartache for the family employing the employee. These are things that our typical Developmental Center took care of when we hired them to work with our child, now it is up to the parents/providers to provide this coverage.
44. I appealed to next year. Service remain in place till 2013
45. I don't know anything about being able to appeal.
46. The one thing I would have liked the Dept to do is to come clean about the fact that kids are losing hours of service with this Redesign. They kept calling it "cost neutral" which implied that everyone would continue to receive the same level of help. However, it is clear that they have chosen to focus the dollars on the young kids and the lower functioning children. They should have said up front that they have evidence-based reasons for doing this and that they had to make hard choices about limited resources. Also, I like the improved focus on family participation because some families just used services as a babysitter before. However, I would have increased this requirement even more and made a rule that higher-functioning kids could still qualify for a lot of support if the families could show that they are fully involved and the child is receiving 24/7 follow-through from them. I'm not sure how this would be accomplished...
47. Bottom line is that the budget set is not adequate for what my son may need and I will be paying out of pocket for services that I cannot afford. I have health insurance but cannot force them to pay for services not covered in my employer's plan. I'm disgusted and fearful of the future for my son.
48. The process still seems to have quirks to work out.
49. The appeal process does not give parents enough time to respond and is written to both intimidate and discourage parents from appealing.
50. this whole process has been absolutely horrendous
51. parents are ignored; DHW glosses over the concerns by saying we are getting an 'array of services'--although the ability to use those services is minimal due to the 'individualized budget' that is a significant take away
52. I think the overall concept is good - but I think it has been made too complicated. I feel that I am educated, and I feel overwhelmed. I wonder what how the overall population is going to handle the change.
53. I have not been informed about the redesign as well as I feel I should be.
54. I am unclear on how this is going to be better for my children. The consistency and time my children are receiving services help them to continue to develop.
55. In Oct we filled out the proper doc for the redesign services (Our son's b-day is Feb) and when I turned them in I was told that we were quick and everything looked like it was in place. I'm surprised that I have not been informed as to what to do to take the next step. No list of support brokers and no budget.
56. I am in the process of trying to decide if I am going to the Family Directed. Feels like I am headed into the "unknown". I am trying to get as much info as possible. Yet, It is not readily available. Especially within the service agencies. The redesign folks are very nice and helpful. But. So many unknowns. All of the new acronyms are

atrocious. All the new names of services will take a while to be familiar with. It could have been made more 'family friendly'. And, we are a high functioning family. I am sure some families will have a lot of trouble with this new service system.

57. We got the letter stating how much our son will receive but have not been contacted by H&W yet. It has been almost a month. Will try to call again on Monday.

58. During the eligibility re-certification it was required for me to bring my daughter to re-do her SIB-R. She is 9 so no questions were asked of her and she sat there the entire time. This was very stressful to myself trying to answer questions and also keep her occupied. My daughter was also becoming bored and agitated, she sat there for 45 minutes and missed school time. If the child will not be needed for the eligibility process, it shouldn't be required to bring them.

59. What am I appealing if I do not know what I am appealing? Appealing the budget without knowing if the budget meets my child's need?

60. Besides the 75% reduction and the attempt to block off access to apply for behavioral services through EPSDT there have been many disturbing issues that develop over time. We are appealing our budget and because of that we have been told the department has a "strict" policy not to talk or answer questions to people that are in the hearings process. The questions we are asking are related to EPSDT and not the budget. It feels like we are being punished for appealing our budget. If we were told how our child could get the medically necessary therapy his doctors prescribed once he was in the redesign we wouldn't care what his budget was. It could be a \$1.00 because we would know he is getting what he is being prescribed. We have concerns with the fair hearing process. Medicaid sent the hearings officer their evidence without sending it to us while we have disclosed all of our evidence to both the hearings officer and Medicaid at the same time. We asked the hearings officer why Medicaid isn't having to follow their own rules and the reply was "this office will not be responding to piece meal questions." It makes us question if the hearings officer won't enforce the rules prior to the hearing why would he rule to enforce Medicaid to follow the rules after the hearing? The hearings officer won't abide by the IDAPA rule that the hearing date and the ruling must be done within 90 days. He consulted Medicaid's lawyer and the department and that they chose the date that worked for them without consulting with us. They scheduled it past the 90 days. At our prehearing we said 9:00 is not a good time because one of us drives the kids to school and we wouldn't be back until 9:15-9:30. It isn't surprising they chose the time of 9:00 for our hearing date so one of us is not present. We understand it is Medicaid's right to have a lawyer but they told us at the prehearing that they would not have a lawyer and 4 days until our original scheduled hearing they vacated the date because they wanted the Attorney General's lawyer representing them. We feel the hearings officer is treating Medicaid lawyer and the Medicaid staff as their time is more important than ours. We just want the same courtesy, if nothing else to show us that they are impartial and fair. We made a public records request on Dec 5th for how the budget was created. On Dec 22nd we got an email stating they had no anticipated date for them to get us the public record. Today is Jan 4th and they still haven't sent us the public records.

61. My concerns are regarding the financial maze and hoops parents are required to jump through to receive any benefits for our children and the lack of education that is given due to an inadequate knowledge of the terms used in the Medicaid system that would prompt the worker or parent to get more information. An average layperson does not educate themselves in the loop holes of Medicaid nor have the wherewithal to know where to begin to get the answers they need without significant research and effort. Needed services are often lost in the delay of processing and valuable time is lost, resources are spent and emotions are exhausted when trying to cope with the needs of your child. Do you really think this is accessible and user-friendly? Is it just another attempt to initiate "systems" and postpone needed care while government fight on who will pay the bill and who will be eligible. Have you any idea what it is the parent goes through just to have it all blow up in their face? I am a parent, I don't mean to be skeptical, but experience has shown me the reality and it seems programs, systems, come and go, but the real problem remains - no access.

62. Again, does the new budget affect my child even if they are not in the Family Directed Services? Nothing was ever said one way or the other online or otherwise.

63. My concerns are that my special needs son is going to have less without his service coordinator that we have chosen.

64. My son's birthdate is in a couple of weeks and I have received no information about how his services will change.

65. Quit stealing money from our children who so badly need it. This is ridiculous and all you're doing is ruining people's lives.

66. Health and Welfare has made promises they knew wouldn't be followed through with - for instance? Yes I have one...Sitting in front of the Legislature the promise was made there would be money available from other sources - of

course they wouldn't specify what other source they were talking about - mainly because THERE IS NO OTHER SOURCE! I for one am REALLY tired of hearing how 'grateful' H&W is that providers are doing what we do. It's a load of horse manure. I have a boy I care for and I've been told by the state nurse he CANNOT be left unattended yet I only receive 21 hours a week in pay. I'm not allowed to get paid while he sleeps - yet I am on call 24 hours a day - hmmm - sounds a lot like slavery to me. I know I have a choice...that's the only difference. If I were to require the services of a PSR worker - or state nurse - or IBI -or service coordinator, they would be able to say "Well, I'm sorry but my hours with him have been used up this month" and he would be out of luck. But if I were to say that - OH MY GOODNESS - I would be in so much trouble!!!! I would either get written up or my license pulled - something would happen. And why? Because he lives in my home? H&W depends on the fact that he is a human and I will consider feelings and not do this as a 'job' but because I care so much FOR SOMEONE ELSE'S CHILD - who quite honestly - could afford to pay for this service themselves but the state pays so they don't have to. Wow - that's quite a racket. And doesn't sound a very legal one.

67. I don't like that habilitative support has to be given all in community settings for DDA's to avoid auditing problems and I dislike that parents are being forced to choose between quality or quantity in therapy. I feel parents are being asked to understand a system that can be confusing even for professional level, trained persons. Redesign is being advertised as offering "more options" but in reality, it is much more limiting. I believe redesign is the way the state is going to take away most services for children with disabilities without coming right out and doing it as they don't want to look like the "bad guys".

68. We had to find out from another care giver concerning failure to receive package in time. We had to find out that the appeals of budget was required even if we didn't choose to go that route any way or we would lose the appeal right after the 28 days, even if we didn't go the budget route.. There are some serious holes and we are already stressed and I assume you guys are too! We fear retribution for our views and comments and elect not to provide contact info. That is indeed a shame. We will continue to strive for truthful information from any available sources and respond to the best of our ability to the changes.

69. Don't recall the Children's Redesign stuff. My TESH service coordinator is good on keeping me informed of what all is going on.

70. The information provided is vague and not clear. The costs of family directed are not clear and the process and what my responsibilities would be are not clear. Without a service coordinator this choice looks like a nightmare. Making any of the choices without a coordinator looks difficult. Would like a brochure or information that is more detailed and clear.

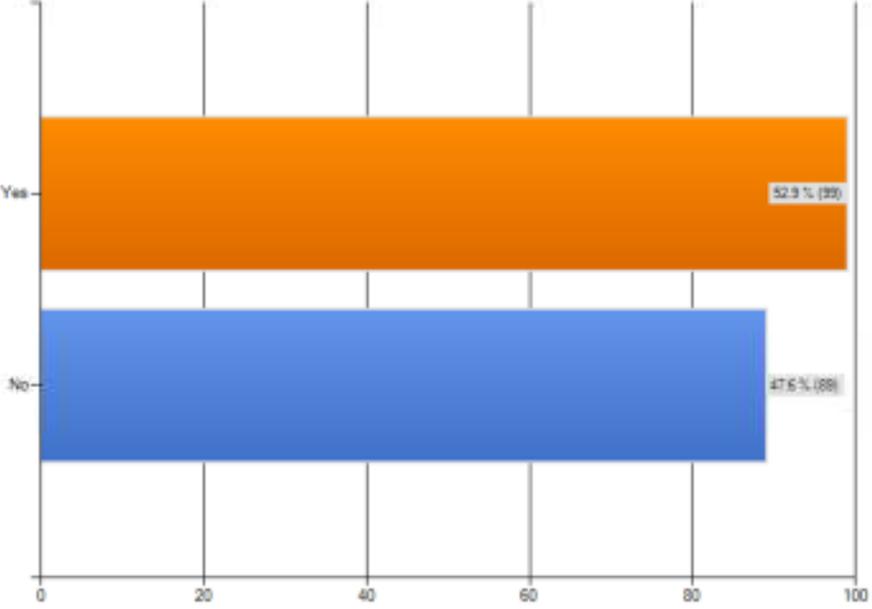
71. the process of transitioning from child to adult services

72. I would like to know what the plan is after this year of opting into the redesign. Will all children be forced to accept the changes/cuts to services?

73. From what I understand, appeals are for show only. No one is actually winning any appeals. On another note, it seems very unfair that kiddo's are not being afforded similar services as what they are already receiving. This was supposed to be a "budget neutral" change, however, it seems to me that many kids will go without much needed services because the Dept. is actually cost cutting instead of staying neutral. A perfect way to see whether it is "neutral" would be to simply compare the child's current budget with what their new budget is and average that over the state. I firmly believe that the data would show a cost savings to Medicaid at the detriment to the children of the state of Idaho.

74. I think the Family Directed plan places an extreme amount of pressure on parents that are already taxed daily to their limits. After our intake eval and acceptance, we have heard NOTHING from anyone about what the next step would be. Our child's birthday has passed. Very frustrating!

75. My main concern is the shortage of Intervention staff under the new guidelines. All provisional personnel are full due to working with children under the current services option and no agency can hire anyone who qualifies under the rules to be a habilitative interventionist because they don't exist. It is frustrating to go to a DHW meeting and be told my child can get intervention, when the reality is that no qualified individuals are available and I need to complete an addendum to transfer my intervention hours to support hours.

<p>19. May we share your contact information with Health and Welfare?</p> <p>Answered Question: 188 Skipped Question: 7</p> <p>Yes: *99 52.9% No: 89 47.6%</p> <p>* While 99 respondents stated they were willing to share their contact information, only 51 left comments and some did not leave their actual contact information.</p>	<p>May we share your contact information with Health and Welfare?</p>  <table border="1"><thead><tr><th>Response</th><th>Percentage</th><th>Count</th></tr></thead><tbody><tr><td>Yes</td><td>52.9%</td><td>99</td></tr><tr><td>No</td><td>47.6%</td><td>89</td></tr></tbody></table>	Response	Percentage	Count	Yes	52.9%	99	No	47.6%	89
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